



FAQ **Indiana State Department of Health Genomics and Newborn Screening Program**

FOR PRIMARY CARE PROVIDERS (PCP)

Q. What is newborn screening (NBS)?

A. Newborn screening is the greatest public health program to date. For Indiana, NBS is a set of three screens: the heel stick, pulse oximetry and the hearing screen. These three screens look for approximately 50 conditions that would otherwise be undetected until symptoms appear.

Q. Who is a primary care provider?

A. A physician, midwife and other healthcare providers.

Q. I am a healthcare provider for mothers, infants, children and fathers alike. Do I have a role in NBS?

A. Yes! Responsibility is transferred to the follow-up provider to ensure screens or confirmatory testing are completed for newborns no longer admitted to the hospital and homebirths

Q. I am a healthcare provider for mothers, infants, children and fathers alike. Do I have a role in the IBDPR?

A. Yes! It is the responsibility of the provider to diagnose and report birth defects to the IBDPR within 60 days. You can find out more on our reporting webpage at <https://www.in.gov/isdh/28279.htm>.

Q. How can I find out more about the state NBS and IBDPR programs?

A. Please visit our webpages, www.NBS.in.gov and www.BirthDefects.in.gov for more information.

Q. Are reportable conditions available online?

A. Yes! The list of reportable birth defects can be found here.

Q: What happens to the dried blood spots (DBS) after results have been reported?

A: The lab stores the DBS for six months and then it is destroyed. If requested, the DBS is stored for three years. DBS are stored because of their value to the family, to quality control and to assurance monitoring.

Q: How do I obtain information for my patient about sickle cell trait for NCAA compliance?

A: Starting in the 2010-2011 academic year, the National Collegiate Athletic Association (NCAA) mandated that all new student-athletes must be tested for the sickle cell trait or if they decline testing, sign a waiver so that their college or university cannot be held liable.

As of 2007, every state nationwide screens newborns for sickle cell disease as a part of their newborn screening panel. Some started screening for sickle cell disease before 2007.

You can request patient results by faxing the NBS Lab, 317-321-2495 with the patient's name, date of birth, mother's name and the hospital where the patient was born.



Q: Who can I reach out to if I receive an out-of-range result?

A: A “positive” or “out-of-range” result indicates that the screen showed signs that the baby may be at a higher risk of having one of the conditions tested. Follow-up testing must be performed immediately to confirm due to the serious nature of the conditions. In this case, you can review the next steps on the patient report faxed to you from the NBS Lab. It is important to follow these directions because the sooner a diagnosis is made, the sooner the baby can be treated. Please call 888-815-0006 or the number listed on the patient report if you have questions or concerns.

Q: Whom should I contact if I don't receive any newborn screening result for my patient?

A: You can request access to INSTEP by emailing ISDHNBS@isdh.IN.gov.

Q: Can the GNBS program assist me in training my staff on NBS best practices and reporting?

A: Yes! The GNBS education specialist is available to meet with stakeholders to ensure best outcomes for Hoosier newborns and children. Please contact our program to request an on-site visit at 888-815-0006 or ISDHNBS@isdh.IN.gov.

Q: Religious waiver be used for refused rescreens?

A: Yes, the state waiver should be fully indicated and signed; therefore, the parents do still need to return to the birthing facility to complete this.

Q. Is NAS screened for through NBS?

A. No, NAS is not screened for through NBS but it is a targeted condition of the IBDPR. The NBS conditions list and the IBDPR reportable conditions can be found online at <http://www.BirthDefects.IN.gov>.

Q. Is there a new/separate consent that needs to be signed for repeat NBS?

A. This is referring to the family's consent to storage of the sample, not the collection. The NBS lab considers each sample separately when it comes to consent for storage, so it needs to be completed with every draw.

Q. What shall a facility do when an infant born at home is brought to the hospital by parents for NBS?

A. By mandate, we encourage homebirths, planned and unintentional, to obtain screening at the nearest birthing facility, local health department or within their chosen pediatrician's office.

Q. If a family is requesting additional NBS resources, where can I direct them?

A. We want families to be informed about their child(s) NBS therefore we have made many resources available to families and providers alike on our webpage at www.NBS.IN.gov.

Q. How long has the IBDPR existed?

A. IBDPR has existed since 1986. For more information about the Indiana Birth Defects and Problems Registry (IBDPR) visit www.BirthDefects.in.gov.

For more information visit www.NBS.in.gov

